

Resource Information

For Families of Infants and Toddlers with Special Health Care Needs

General Information

General information about birth defects is available from the following groups.

- ▶ **March of Dimes Birth Defect Foundation**
Phone: 1-888-MODIMES
(1-888-663-4637)
www.marchofdimes.com
- ▶ **National Center on Birth Defects and Developmental Disabilities**
www.cdc.gov/ncbddd
- ▶ **Genetic Alliance**
Phone: 1-800-336-GENE
(1-800-336-4363)
www.geneticalliance.org
- ▶ **Virginia's Information and Referral System (I&R)**
Phone: 1-800-230-6977
www.vaiandr.com



**Division of Child and Adolescent Health
Pediatric Screening and Genetic Services
Virginia Genetics Program
1-800-523-4019
www.vahealth.org/genetics**

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This brochure was designed to provide you with information that may be helpful to you and your child. You were sent this guide because the Virginia Department of Health was informed that you might have a child with a special health care need.

Your child's name may have also been sent to a program in your area that can help you receive needed services. The Early Intervention and Care Connection for Children programs can help make sure your child's growth, developmental, and healthcare needs are met.

Early Intervention

▶ The **Infant & Toddler Connection of Virginia** is a system of services that promotes the greatest possible development for infants and toddlers with developmental delays or disabilities. The system has been established because of the Individuals with Disabilities Education Act (IDEA), Part C - Early Intervention.

Children ages 0-36 months with developmental disorders and/or diagnosed disabling conditions that have a high chance of resulting in delays are eligible to receive early intervention services.

Early intervention services include:

- Child-find services to identify and refer eligible children and their families to the Infant & Toddler Connection of Virginia.
- Multidisciplinary evaluation and assessment to determine initial and ongoing eligibility.
- Service coordination to assist families in obtaining needed services.
- 16 early intervention direct services, such as occupational therapy, physical therapy, and speech-language therapy.

For more information

Infant & Toddler Connection of Virginia
Phone: 1-800-234-1448 www.infantva.org

Special Health Care

▶ The **Children with Special Health Care Needs Program (CSHCN)** promotes the health and development of children who have special health care needs. It does this by working with families, service providers, and communities. The Care Connection for Children centers help families connect with:

- Local health care providers who work with children who have special health care needs.
- Special health insurance programs.
- Local resources.
- School programs.
- Other families who have similar situations.

A statewide and regional resource directory is available at: www.specialneedsresourcesva.org

For more information:

Virginia Department of Health
CSHCN Program
Phone: 804-864-7706
www.vahealth.org/specialchildren

▶ The **Child Development Services Program** provides diagnostic assessments, care planning, and referrals for children who might have developmental and behavioral disorders. Examples of these conditions include:

- Developmental delay.
- Attention deficit disorder.
- Emotional and behavioral concerns.

For more information:

Virginia Department of Health
Phone: 804-864-7706
www.vahealth.org/specialchildren

Special Education

► The **Virginia Department of Education** offers special education programs for children with disabilities.

Special education includes instruction conducted in a general education or special education classroom, home, hospital, or separate school setting. These services are provided at no cost to parents.

For more information:

Parent Resources
Virginia Department of Education
Special Education and Student Services
Phone: 1-800-422-2083
www.pen.k12.va.us/VDOE/sess

Family Support

► **Family Voices** is a national organization that provides information and education regarding the care of children with special health needs. Each state has a volunteer coordinator who works with families to bring their expertise and stories to policymakers, health professionals, and other families.

For more information:

Phone: 1-888-835-5669
www.familyvoices.org

► **Parent to Parent** is an organization that connects parents with a trained volunteer support parent whose child has the same disability, illness, issue, or concern.

For more information:

Phone: 804-795-1481
www.ptpofva.com

► The **Parent Educational Advocacy Training Center** serves families of children with disabilities in Virginia. It provides information and education to families to promote success in school and community life.

For more information:

Phone: 1-800-869-6782
www.peatc.org

► The **Arc of Virginia** is a statewide advocacy organization made up of individuals with disabilities. It also includes families and professionals who care about people who have mental retardation and related developmental disabilities.

For more information:

Phone: 804-649-8481
www.arcofva.org

Financial Support

► **FAMIS** is Virginia's program that helps working families provide health insurance to their children. FAMIS stands for Family Access to Medical Insurance Security. Services covered by FAMIS include doctor visits, hospital visits, medicine, dental care, emergency care, and vision care.

For more information:

FAMIS
Phone: 1-866-873-2647
www.famis.org

► **FAMIS Plus** is Virginia's name for children's Medicaid. It provides medical care for children in families with lower or no income.

To apply for FAMIS Plus contact FAMIS or the Department of Social Services in the city or county in which you live.

For more information:

Virginia Department of
Medical Assistance Services
Phone: 1-800-230-6977
www.dmas.virginia.gov

► **Supplemental Security Income (SSI)** is a federal program that provides monthly payments and enables state Medicaid coverage for children with severe mental, emotional, and physical disabilities. The family income must meet certain guidelines.

For more information:

Social Security Administration
Phone: 1-800-722-1213
www.ssa.gov

VaCARES: Virginia Congenital Anomaly Reporting and Education System

► The **Virginia Department of Health** manages the Virginia birth defect registry, which is called the Virginia Congenital Anomaly Reporting and Education System (VaCARES).

Virginia law requires that hospitals report to the health department any child under the age of 2 years who has a birth defect. These reports are an important part of VaCARES.

VaCARES reports are used for the following reasons:

- To determine possible causes of birth defects.
- To improve the treatment of birth defects.
- To tell parents about helpful resources.

Information in VaCARES is confidential, and regulated by Virginia law. The information can be used only to offer appropriate services to families, for prevention education, and for research on causes of birth defects.

For more information:

Virginia Department of Health
Virginia Genetics Program
Phone: 804-864-7712
www.vahealth.org/genetics

